

Caregiving
Across the
United
States

**Caregivers of
Persons with
Alzheimer's
Disease or
Dementia in
Illinois,
Louisiana,
Ohio, and the
District of
Columbia**

Data from the 2009 Behavioral Risk Factor Surveillance System

Prepared by:

Erin DeFries Bouldin, MPH

Elena Andresen, PhD



Florida Office on Disability and Health
Department of Epidemiology and Biostatistics
College of Public Health and Health Professions
University of Florida
<http://fodh.php.ufl.edu>

This report was funded by the Alzheimer's Association.



www.alz.org

Acknowledgement:

We are grateful to the BRFSS Coordinators in Illinois, Louisiana, Ohio, and Washington, D.C. for their assistance and expertise: Bruce Steiner, Todd Griffin, Patricia Coss, and Tracy Garner.

Table of Contents

EXECUTIVE SUMMARY	2
CAREGIVING IN THE UNITED STATES	3
ALZHEIMER'S DISEASE & DEMENTIA IN THE UNITED STATES	3
THE BRFSS AND THE CAREGIVER MODULE	3
POPULATION PROFILES	4
METHODS	5
RESULTS	6
CONCLUSIONS.....	16
REFERENCES	18

Tables

Table 1. Number and percent of residents in Illinois, Louisiana, Ohio, and Washington, D.C. who are under age 18 and age 65 or older in 2000 and 2030 according to US Census Projections. Page 5

Table 2. Weighted caregiving experience characteristics of caregivers of persons with Alzheimer's disease or dementia and caregivers of persons without Alzheimer's disease or dementia in Illinois, Louisiana, Ohio, and Washington, D.C.; Behavioral Risk Factor Surveillance System (BRFSS), 2009. Page 10

Table 3. Weighted demographic and health behavior characteristics of caregivers of persons with Alzheimer's disease or dementia and caregivers of persons without Alzheimer's disease or dementia in Illinois, Louisiana, Ohio, and Washington, D.C.; Behavioral Risk Factor Surveillance System (BRFSS), 2009. Page 13

Executive Summary

This report summarizes data from the 2009 Behavioral Risk Factor Surveillance System (BRFSS) in three states – Illinois, Louisiana, and Ohio – and the District of Columbia. The BRFSS is a telephone survey conducted annually in the United States and its territories to assess the health and health behaviors of non-institutionalized adults. The BRFSS is a joint effort of the Centers for Disease Control and Prevention (CDC) and state departments of health.

In 2009, states had the option of adding the Caregiving Module, a set of ten cognitively-tested and CDC-approved questions about informal caregiving. The states and district included in this report are the only areas that chose to include the Caregiving Module in that year. The purpose of this report is to compare the caregiving experiences, demographic factors, and health behaviors of caregivers who provided care to a person with Alzheimer’s disease or dementia to caregivers who provided care to a person with any other type of health condition or disability.

Caregivers of persons with Alzheimer’s disease differed in some ways from other caregivers in these states. Their care recipients tended to be older than care recipients without Alzheimer’s disease or dementia and they also were more often female. Caregivers of persons with Alzheimer’s disease or dementia were more likely to be providing care for a parent or parent-in-law and were more likely to report that they provided the most help with self-care like moving around or eating, bathing, or dressing compared to caregivers of persons without Alzheimer’s disease or dementia. These self-care activities indicate caregivers of persons with Alzheimer’s disease or dementia may be providing more intense care than other caregivers. Although both groups of caregivers spent a similar amount of time each week providing care, caregivers of persons with Alzheimer’s disease or dementia had provided care for longer than other caregivers. They also were more likely to report that caregiving created stress and that it created or aggravated health problems compared to other caregivers. Conversely, caregivers of persons without Alzheimer’s disease or dementia were more likely to report that caregiving created a financial burden than were caregivers of persons with Alzheimer’s disease or dementia. Like their care recipients, caregivers of persons with Alzheimer’s disease or dementia tended to be older and were more likely to be female than were other caregivers. Caregivers of persons with Alzheimer’s disease or dementia were less likely to be current smokers and were more likely to report having health insurance and a personal doctor (possibly related to older average age and the availability of Medicare) compared to other caregivers. On most other demographic and health characteristics (including income, employment, disability, general health status, mental distress, physical activity, and alcohol consumption), caregivers were similar regardless of the diagnosis of the person to whom they provided care.

The 2009 BRFSS data provide a population-based snapshot of caregiving in Illinois, Louisiana, Ohio, and Washington, D.C. and suggest that there may be important differences between caregivers based on whether their care recipients have been diagnosed with Alzheimer’s disease or dementia. Based on these data, it is possible that caregivers of persons with Alzheimer’s disease or dementia may need interventions to reduce stress and prevent health problems related to caregiving more than other caregivers. They also may need support for a longer period than other caregivers. Additional research at the state level is needed to more fully assess these needs and differences among caregivers.

Caregiving in the United States

America's 53.4 million caregivers form an integral and frequently unrecognized part of the health care team, providing an estimated \$257 to \$389 billion in unpaid care to individuals with disabilities and chronic diseases.¹⁻³ These informal caregivers may be a family member, friend, or neighbor of a person with a disability or chronic health condition.

There are both positive and negative health outcomes and experiences associated with caregiving. The person providing care, or caregiver, may experience improved well-being when caring for another, but she may also neglect her own health or feel added physical, emotional, and financial strain because of caregiving duties. Research on caregiving has been, and continues at multiple levels. On an individual level, investigators determine the risks for poor health outcomes and assess the effect of providing support to caregivers based on attributes of care such as the care recipient's diagnosis, the amount of time spent caring, or the relationship between caregiver and care recipient. At the population level, researchers are working to understand caregivers and their health outcomes, and answer questions such as how many caregivers there are in the U.S., what types of care they provide, and for how long they provide this care. Understanding caregiving across multiple levels allows us to understand the impact of caregiving, to plan for services and other needs to support caregivers and care recipients, and to deliver appropriate interventions to caregivers.

Alzheimer's Disease and Dementia in the United States

Alzheimer's disease, the most common cause of dementia, is the 6th leading cause of death in the United States.⁴ It is estimated that 5.4 million people in the US have been diagnosed with Alzheimer's disease and that it costs approximately \$183 billion annually.⁴ Nearly 15 million Americans provide informal caregiving for people with Alzheimer's disease.⁴

Research suggests that caregivers for people with Alzheimer's disease, or dementia spend more hours providing care than other types of caregivers and provide more intense care – like assistance with eating, bathing, dressing, or other so-called activities of daily living – than caregivers of persons without Alzheimer's disease or dementia.⁴ This may lead to more negative physical and mental health outcomes. Also, caregivers for people with cognitive impairment tend to be older than other caregivers, and potentially have more disability and are more frail themselves.⁵ Thus, this specific subgroup of caregivers is of interest for planning and program development.

The BRFSS and the Caregiver Module

Currently, the prevalence of caregiving and the health impacts of caregiving are not known at the state and local level across the U.S. State and federal agencies, as well as private organizations are concerned about issues surrounding caregiving and could employ population-based caregiving data to design needed programs and interventions to address this increasingly important public health issue. Many community and public health groups are interested in specific health conditions as they relate to caregiving—notably cancer, Alzheimer's disease and dementia, and

developmental disabilities. Thus, there is an emerging and increasing audience requiring this information. Learning more about caregivers and how their caregiving activities impact their risk of poor health outcomes will improve our understanding of how to provide support to them, in turn improving the ability of care recipients to maintain independence and experience an improved quality of life.

Since 2004, the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention (CDC) has made a systematic attempt to identify and describe caregivers as part of the total health care system, and to identify public health dimensions of caregiving. One result of this work has been the development of the Caregiver Module, a series of questions about caregivers and their experiences that can be added to the Behavioral Risk Factor Surveillance System (BRFSS).⁶ The BRFSS is a state-based, random-digit-dialed (RDD) telephone survey of non-institutionalized U.S. adults aged 18 and older. In other words, only adults living in community settings who have a landline telephone may be sampled for this survey. (Institutions include places like group homes, college dormitories, military housing, and jails.) This survey is administered by state health agencies, territories, and in the District of Columbia with assistance from the CDC.⁷ Each state asks a common set of questions during a calendar year (known as the “core” questionnaire) and may choose to ask additional questions about specific topics of interest through the use of CDC-approved modules or through the addition of state-added questions (questions not part of a CDC-approved module).

The Caregiver Module, now one of the CDC-approved options modules available to all states, is designed to collect information about adult caregivers who care for individuals with a disability or chronic condition regardless of the individual’s age, level of need, or diagnosis. The module is a series of 10 questions that asks caregivers about the person for whom they provide care, the type of care they provide, the amount of care they provide, and difficulties they face in providing care. Data are weighted so that people who respond to the survey represent the entire state or territory from which respondents are sampled based on age, gender, and race.

Population Profiles

According to US Census Bureau projections, the age profile of all states will change considerably by the year 2030: the United States population is aging. Table 1 displays the projected changes in the population structure of Illinois, Louisiana, Ohio, and Washington, D.C. over the coming decades. In the three states, Illinois, Louisiana, and Ohio, the proportion of the population under age 18 is expected to decrease from just over one-quarter (25-27%) of the population in 2000 to just under one-quarter (23-24%) of the population in 2030. During the same time period, the proportion of the population age 65 or older in the three states is expected to grow from just over one in ten (12-13%) to around one in five (18-20%). The age trend is projected to be different in Washington, D.C. from most other states. There, the proportion of the population under age 18 is expected to increase from 20% in 2000 to 23% in 2030. As in the rest of the nation, the proportion of the

population age 65 and older is expected to increase (from 12% in 2000 to 13% in 2030), though much less dramatically than elsewhere. Because the risks of Alzheimer’s disease, dementia, and disability increase with age, it is expected that as the population ages, the need for informal caregivers will increase as well.

Table 1. Number and percent of residents in Illinois, Louisiana, Ohio, and Washington, D.C. who are under age 18 and age 65 or older in 2000 and 2030 according to US Census Projections.

State	Population under age 18				Population age 65 and older			
	2000		2030		2000		2030	
	No.	%	No.	%	No.	%	No.	%
Illinois	3,245,451	26.1	3,259,113	24.3	1,500,025	12.1	2,412,177	18.0
Louisiana	1,219,799	27.3	1,149,939	23.9	516,929	11.6	994,212	19.7
Ohio	2,888,339	25.4	2,640,671	22.9	1,507,757	13.3	2,357,022	20.4
Washington, D.C.	114,992	20.1	100,589	23.2	69,898	12.2	58,238	13.4

Source: US Census Bureau. US Population Projections, Table 5: Interim Projections: Population under age 18 and 65 and older: 2000,2010, and 2030. Available at <http://www.census.gov/population/projections/PressTab5.xls>.

Methods

To study the characteristics and health of caregivers and their care recipients in Illinois, Louisiana, Ohio, and Washington, D.C., the Caregiver Module was added to the 2009 BRFSS in each of these states. The BRFSS allows not only for the analysis of demographic differences among caregivers and non-caregivers but also assesses health behaviors, such as exercise frequency, smoking status, and alcohol use. In addition, through the use of this module, caregivers can be compared to non-caregivers on quality of life measures such as general life satisfaction, the amount of emotional and social support received, and self-reported general health status. Because of the complex sampling design used on the BRFSS, all results presented in this report are weighted using SAS 9.2. These weights are used so that BRFSS respondents represent the entire state’s population by age, race, and gender.

During 2009, a total of 28,207 BRFSS respondents in Illinois, Louisiana, Ohio, and Washington, D.C. provided a valid response (yes or no) to the question, “People may provide regular care or assistance to someone who has a long-term illness or disability. During the past month, did you provide any such care or assistance to a family member or friend?” Of these, 6,872 or 24.1% (weighted) said “yes” to this question. These respondents were classified as caregivers and answered the remaining Caregiver Module questions about themselves and their care recipient. (If a caregiver reported providing care to more than one recipient, the caregiver was asked to answer the Caregiver Module questions based on the recipient to whom he or she provided the most care). A total of 4,250 caregivers provided a valid response (a specific health condition) to the question, “What do you think or what has a doctor said is the major health problem that your [care recipient] has?” Among those caregivers, 354 or 7.3% (weighted) said Alzheimer’s disease or dementia to this question. In this report, these respondents are considered to be caregivers of persons with Alzheimer’s disease or dementia. In Tables 2 and 3, the percentages

and 95% Confidence Intervals are based on the number of valid responses for each item; in other words, individuals who did not answer a question were not excluded from the overall analysis. In all cases other than income, fewer than 5% of the responses were missing and are not reported in the results. For income there is a separate row for missing/refused respondents since there were a substantial number.

Results

Information about the caregiving experience of caregivers of people with and without Alzheimer's disease or dementia appears in Table 2. Most care recipients were women, though care recipients with Alzheimer's disease or dementia were significantly more likely to be female (74 % of care recipients with Alzheimer's disease or dementia and 63% of care recipients without Alzheimer's disease or dementia). Care recipients with Alzheimer's disease or dementia were significantly older than care recipients without Alzheimer's disease or dementia (mean ages: 83 for care recipients with Alzheimer's disease or dementia and 64 for care recipients without Alzheimer's disease or dementia). Care recipients were most commonly a family member of the caregiver in both groups. Among caregivers of persons with Alzheimer's disease or dementia, 63% were providing care for a parent, 8% cared for a spouse or partner, and 22% cared for some other family member (sibling, grandparent, etc.). Caregivers of persons without Alzheimer's disease or dementia most commonly cared for a family member other than a parent or spouse (33% provided care for an "other" family member, 43% for a parent, and 9% for a spouse or partner). As noted above, caregivers were asked to identify the care recipient's major health condition that led to their need for care. Among caregivers of persons without Alzheimer's disease or dementia, the most common diagnoses reported were cancer (10%), heart disease (10%), diabetes (8%), and stroke (6%). Most caregivers of persons with Alzheimer's disease or dementia reported their care recipients experienced a change in thinking or remembering in the past year (93%). These caregivers were significantly more likely to report a cognitive change than were caregivers of persons without Alzheimer's disease or dementia (46%).

Caregivers reported providing the most help to the care recipient in a variety of areas. When asked to identify the area in which their care recipient needed the most help, one-third (33%) of all caregivers reported household care, regardless of the care recipient's diagnosis. Equally commonly reported by caregivers of persons with Alzheimer's disease was the care recipient's need for self-care assistance (33%); only 19% of caregivers of persons without Alzheimer's disease or dementia reported the care recipient needing the most help with self-care. The second most commonly reported area of assistance among these caregivers of persons without Alzheimer's disease or dementia was transportation outside the home at 26%.

Caregivers of persons with Alzheimer's disease or dementia had provided care for a significantly longer period than had caregivers of persons without Alzheimer's disease or dementia. Around 10% of caregivers of persons with Alzheimer's disease or dementia had been providing care for 3 months or less compared to 30% of caregivers of persons without Alzheimer's disease or dementia. One in five caregivers in both groups had provided care for 5 years or longer. The

hours of care provided in an average week were similar across caregiving groups, with 48% of caregivers of persons with Alzheimer's disease or dementia and 55% of other caregivers providing 0-8 hours of care in an average week. Nineteen percent of caregivers of persons with Alzheimer's disease or dementia and 14% of caregivers of persons without Alzheimer's disease or dementia provided 40 hours of care per week or more. When asked the greatest difficulties faced personally, caregivers of persons with Alzheimer's disease or dementia most often said that caregiving created stress (37%); they were significantly more likely to report this problem compared to caregivers of persons without Alzheimer's disease or dementia (24%). Caregivers of persons without Alzheimer's disease or dementia most often said that caregiving did not create any difficulties (35%; significantly higher than the 23% of caregivers of persons with Alzheimer's disease or dementia). Caregivers of persons with Alzheimer's disease or dementia were also significantly more likely to report that caregiving created or aggravated health problems (6% compared to 3% of caregivers of persons without Alzheimer's disease or dementia) and significantly less likely to report that caregiving created a financial burden (3% compared to 7% of caregivers of persons without Alzheimer's disease or dementia).

Demographic and health behavior characteristics of caregivers of people with and without Alzheimer's disease or dementia are presented in Table 3. Caregivers of persons with Alzheimer's disease or dementia were more likely to be female compared to other caregivers, though the majority of all caregivers were female (70% of caregivers of persons with Alzheimer's disease or dementia and 59% of caregivers of persons without Alzheimer's disease or dementia). Caregivers of persons with Alzheimer's disease or dementia were older than caregivers of persons with other diagnoses (mean ages: 52 for caregivers of persons with Alzheimer's disease or dementia and 46 for caregivers of persons without Alzheimer's disease or dementia). Caregivers of persons with and without Alzheimer's disease or dementia had similar levels of educational attainment. For example, 35% of caregivers in both groups had earned a college or more advanced degree. Most caregivers were employed, students or homemakers (71% of caregivers regardless of the care recipient's diagnosis) and less than one in five was retired (19% of caregivers of persons with Alzheimer's disease or dementia and 15% of caregivers of persons without Alzheimer's disease or dementia). Caregivers of persons with Alzheimer's disease or dementia were more likely to be married or the member of an unmarried couple (73% compared to 63% of caregivers of persons without Alzheimer's disease or dementia). More than one in three caregivers reported having at least one child under the age of 18 living in the household (34% of caregivers of persons with Alzheimer's disease or dementia and 41% of caregivers of persons without Alzheimer's disease or dementia). Annual household income was similar for both groups of caregivers and around half reported \$50,000 or more (52% of caregivers of persons with Alzheimer's disease or dementia and 45% of caregivers of persons without Alzheimer's disease or dementia). Racial and ethnic distributions were different by the care recipient's diagnosis. The majority of caregivers reported their race as white and ethnicity as non-Hispanic (81% of caregivers of persons with Alzheimer's disease or dementia and 69% of caregivers of persons without Alzheimer's disease or dementia).

However, caregivers of persons without Alzheimer's disease or dementia were more likely to report a race other than white; 18% reported their race as black and 7% reported a race other than white or black (compared to 13% and 5% among caregivers of persons with Alzheimer's disease or dementia, respectively). Hispanic ethnicity was uncommon in both groups of caregivers: 1% of caregivers of persons with Alzheimer's disease or dementia and 2% of caregivers of persons without Alzheimer's disease or dementia.

Respondents were categorized as having a disability according to the BRFSS definition: If respondents answered "yes" to either of two questions: "Are you limited in any way in any activities because of physical, mental, or emotional problems," or "Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone," they were classified as having a disability. The prevalence of disability among caregivers of persons with Alzheimer's disease or dementia was similar to the prevalence of disability among caregivers of persons without Alzheimer's disease or dementia (23% and 21%, respectively).

More than 90% of caregivers in both groups reported they were satisfied or very satisfied with their lives in general (96% of caregivers of persons with Alzheimer's disease or dementia and 94% of caregivers of persons without Alzheimer's disease or dementia). Emotional support of the respondents was assessed by the question: "How often do you get the social or emotional support you need?" Around eight in ten caregivers (82% of caregivers of persons with Alzheimer's disease or dementia and 75% of caregivers of persons without Alzheimer's disease or dementia) reported always or usually receiving the social and emotional support needed. Ratings of general health among both groups of caregivers were also similar; 83% of caregivers in both groups reported their general health was excellent, very good, or good. Health related quality of life (HRQOL) was assessed using the following variables: physical unhealthy days in the last 30 days, mental unhealthy days in the last 30 days, general life satisfaction, emotional support, and general health status. The number of physical unhealthy days was assessed in the question: "Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?" Both types of caregivers had similar average number of days in the past month that their physical health was not good; 4.1 and 3.9 respectively. Mentally unhealthy days were assessed as: "Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?" The mean number of days of poor mental health days was similar for caregivers of people with Alzheimer's disease or dementia (5.3 days) and other caregivers (4.3 days). The question about poor mental health days also can be used to create a variable called frequent mental distress, defined as reporting 14 or more days of poor mental health in the past 30 days. This measure was also similar across the two groups of caregivers; 16% of caregivers of persons with Alzheimer's disease or dementia and 13% of caregivers of persons without Alzheimer's disease or dementia had frequent mental distress.

Measures of health and health behaviors were very similar across the two caregiving groups. Approximately eighty percent of caregivers reported engaging in some form of physical activity outside of work (80% of caregivers of persons with Alzheimer's disease or dementia and 79% of caregivers of persons without Alzheimer's disease or dementia). Among caregivers of persons with Alzheimer's disease or dementia, about one in three (35%) were classified as being neither overweight nor obese (body mass index [BMI] of 18.5-24.9), 33% were overweight (BMI of 25.0-29.9), and 32% were obese (BMI \geq 30.0). Similarly, 36% of caregivers of persons without Alzheimer's disease or dementia were in the healthy BMI range, 32% were considered overweight, and 32% were obese. More than half of caregivers reported they had never smoked (60% of caregivers of persons with Alzheimer's disease or dementia and 53% of caregivers of persons without Alzheimer's disease or dementia). Caregivers of persons with Alzheimer's disease or dementia were less likely to be current smokers compared to other caregivers (15% compared to 25%).

The CDC defines heavy drinking as more than two drinks per day for men and more than one drink per day for women. Binge drinking is defined as men having five or more drinks on one occasion, and women having four or more drinks on one occasion. Eight percent of caregivers of people with Alzheimer's disease or dementia and 4% of caregivers of persons without Alzheimer's disease or dementia were classified as having heavy alcohol consumption. Fourteen percent of caregivers of persons with Alzheimer's disease or dementia and 17% of caregivers of persons without Alzheimer's disease or dementia were classified as binge drinking in the past month.

Most caregivers had some form of health insurance coverage; 93 % of caregivers of persons with Alzheimer's disease or dementia and 83% of caregivers of persons without Alzheimer's disease or dementia said they had some type of health plan. Likewise, most respondents had one or more physicians who they thought of as their personal care provider (95% of caregivers of persons with Alzheimer's disease or dementia and 85% of caregivers of persons without Alzheimer's disease or dementia). Both of these measures (health coverage and a personal physician) were significantly higher among caregivers of persons with Alzheimer's disease or dementia. When it came to covering costs for medical needs, caregivers of persons with Alzheimer's disease or dementia were significantly less likely to report not going to the doctor when they needed to because of cost than were caregivers of persons without Alzheimer's disease or dementia (9% compared to 20%).

Table 2. Weighted caregiving experience characteristics of caregivers of persons with Alzheimer’s disease or dementia and caregivers of persons without Alzheimer’s disease or dementia in Illinois, Louisiana, Ohio, and Washington, D.C.; Behavioral Risk Factor Surveillance System (BRFSS), 2009.

Variable	Category	Caregivers of Persons with Alzheimer’s disease or dementia	Caregivers of Persons without Alzheimer’s disease or dementia
		Percent (95% CI)	Percent (95% CI)
Care recipient gender*	Female	73.9 (67.4-80.3)	63.4 (60.7-66.1)
Care recipient age*	0-64	1.5 (0.2-2.1)	41.3 (38.5-44.0)
	65-74	9.4 (4.1-14.7)	17.6 (15.4-19.8)
	75-84	45.5 (37.4-53.6)	22.9 (20.8-25.1)
	85 or older	43.9 (36.0-51.9)	18.2 (16.3-20.1)
Care recipient’s relationship to caregiver*	Parent or Parent-in-Law	62.9 (55.1-70.6)	42.7 (40.0-45.4)
	Spouse	7.8 (4.1-11.5)	8.8 (7.6-10.0)
	Other relative	21.7 (14.6-28.7)	32.6 (29.9-35.2)
	Non-relative	7.6 (4.2-11.1)	15.9 (13.8-18.1)
Care recipient’s major health problem as identified by the caregiver	Alzheimer’s disease or dementia	100.0	--
	Cancer	--	10.3 (8.7-11.9)
	Heart disease	--	10.0 (8.3-11.7)
	Diabetes	--	8.1 (6.4-9.8)
	Stroke	--	6.4 (5.2-7.7)

*Indicates statistically significant difference.

Variable	Category	Caregivers of Persons with Alzheimer's disease or dementia	Caregivers of Persons without Alzheimer's disease or dementia
		Percent (95% CI)	Percent (95% CI)
Cognitive status change*	Care recipient experienced a change in thinking or remembering in the past year	93.0 (89.3-96.8)	45.8 (43.1-48.6)
Area in which care recipient needs most help	Self-care*	32.6 (24.9-40.2)	18.8 (16.8-20.9)
	Household care	32.6 (24.5-40.8)	33.3 (30.7-36.0)
	Communicating with others	4.5 (0.3-8.6)	3.0 (2.1-3.9)
	Learning, remembering, confusion*	12.6 (7.1-18.0)	1.6 (0.9-2.3)
	Seeing or hearing	1.1 (0.0-3.1)	1.0 (0.5-1.5)
	Moving around	2.8 (0.3-5.4)	6.7 (5.3-8.1)
	Transportation outside the home*	11.3 (6.9-15.7)	25.6 (23.0-28.1)
	Getting along with people	0.0 (0.0-0.1)	1.0 (0.6-1.4)
	Feeling anxious or depressed*	2.5 (0.6-4.4)	9.0 (7.1-10.8)
Length of care*	0-3 months	10.6 (5.6-15.5)	29.3 (26.5-32.0)
	4-12 months	23.5 (16.3-30.6)	18.1 (16.0-20.2)
	13-24 months	19.5 (12.7-26.3)	12.0 (10.1-13.9)
	25-60 months	26.0 (19.2-32.7)	20.1 (18.0-22.1)
	More than 5 years	20.4 (14.1-26.8)	20.6 (18.6-22.6)

*Indicates statistically significant difference.

Variable	Category	Caregivers of Persons with Alzheimer's disease or dementia	Caregivers of Persons without Alzheimer's disease or dementia
		Percent (95% CI)	Percent (95% CI)
Hours of care provided per week	0-8	48.3 (40.1-56.6)	54.5 (51.5-57.3)
	9-19	20.8 (13.6-28.1)	16.5 (14.6-18.5)
	20-39	11.7 (5.5-17.9)	15.3 (13.3-17.4)
	40 or more	19.1 (12.3-25.9)	13.7 (11.7-15.7)
Greatest difficulty faced by caregiver	Financial burden*	2.9 (1.1-4.6)	7.4 (5.9-9.0)
	Not enough time for him/herself	10.5 (6.2-14.9)	8.4 (7.0-9.9)
	Not enough time for family	4.7 (1.4-7.9)	4.9 (3.7-6.1)
	Interferes with work	2.1 (0.5-3.7)	3.1 (2.2-4.0)
	Creates or aggravates health problems*	5.9 (1.9-9.9)	2.7 (1.9-3.5)
	Affects family relationships	8.3 (2.9-13.7)	5.6 (4.1-7.1)
	Creates stress*	36.5 (28.3-44.7)	23.6 (21.3-25.9)
	Another difficulty	6.1 (2.1-10.0)	8.6 (6.6-10.7)
	No difficulty*	22.9 (16.9-29.0)	35.5 (33.0-38.1)

*Indicates statistically significant difference.

Table 3. Weighted demographic and health behavior characteristics of caregivers of persons with Alzheimer’s disease or dementia and caregivers of persons without Alzheimer’s disease or dementia in Illinois, Louisiana, Ohio, and Washington, D.C.; Behavioral Risk Factor Surveillance System (BRFSS), 2009.

Variable	Categories	Caregivers of Persons with Alzheimer’s disease or dementia	Caregivers of Persons without Alzheimer’s disease or dementia
		Percent (95% CI)	Percent (95% CI)
Gender*	Female	70.3 (62.1-78.4)	59.2 (56.3-62.0)
Age*	18-34	15.5 (8.1-22.8)	27.0 (24.0-30.1)
	35-44	12.1 (7.4-16.7)	18.9 (16.7-21.0)
	45-54	27.8 (20.2-35.5)	22.9 (20.9-24.8)
	55-64	26.2 (19.7-32.7)	17.5 (15.8-19.1)
	65+	18.4 (12.9-23.9)	13.8 (12.4-15.2)
Education	Less than high school	32.7 (24.9-40.4)	33.5 (30.9-36.1)
	High school degree or equivalent	32.5 (24.6-40.4)	31.0 (28.4-33.5)
	College degree or beyond	34.8 (27.6-42.1)	35.5 (32.9-38.1)
Employment status	Employed, student, or homemaker	70.8 (63.8-77.8)	71.3 (68.9-73.7)
	Retired	18.8 (13.4-24.3)	14.8 (13.3-16.3)
	Out of work or unable to work	10.3 (5.0-15.7)	13.9 (11.8-16.0)
Marital status*	Married/Coupled	72.8 (65.7-78.0)	63.1 (60.3-65.9)
Children in household	At least one child under age 18 lives in household	34.1 (26.3-41.8)	41.5 (38.7-44.3)

*Indicates statistically significant difference.

Variable	Categories	Caregivers of Persons with Alzheimer's disease or dementia	Caregivers of Persons without Alzheimer's disease or dementia
		Percent (95% CI)	Percent (95% CI)
Household Income	Less than \$15,000	4.6 (1.4-7.8)	6.2 (5.1-7.3)
	\$15,000-\$24,999	9.8 (5.8-13.8)	16.5 (14.3-18.7)
	\$25,000-\$34,999	10.7 (5.1-16.3)	10.2 (8.4-12.0)
	\$35,000-\$49,999	13.2 (8.7-17.7)	13.9 (12.0-15.8)
	\$50,000 or more	52.4 (44.4-60.4)	45.5 (42.8-48.3)
	Not reported or missing	9.3 (4.7-13.9)	7.6 (6.2-8.9)
Race/ethnicity*	White only, non-Hispanic	81.0 (73.4-88.6)	68.6 (65.7-71.5)
	Black only, non-Hispanic	12.8 (5.9-19.8)	18.0 (15.8-20.2)
	Other only, non-Hispanic	4.5 (0.7-8.3)	7.4 (5.3-9.5)
	Multiracial, non-Hispanic	0.3 (0.0-0.6)	3.9 (2.6-5.3)
	Any race, Hispanic	1.4 (0.0-3.4)	2.0 (1.0-3.1)
Disability status	Respondent has a disability	22.7 (15.8-29.5)	21.2 (19.2-23.3)
General life satisfaction	Very Satisfied/Satisfied	95.7 (93.3-98.2)	93.7 (92.3-95.1)
Emotional support	Always or usually receive support needed	81.9 (75.5-88.3)	75.2 (72.5-77.8)
General health	Excellent, very good, or good	83.1 (76.1-90.1)	83.4 (81.4-85.4)

*Indicates statistically significant difference.

Variable	Categories	Caregivers of Persons with Alzheimer's disease or dementia	Caregivers of Persons without Alzheimer's disease or dementia
		Percent (95% CI)	Percent (95% CI)
Frequent mental distress	14 days or more of poor mental health in the past 30 days	16.1 (9.0-23.1)	12.7 (10.8-14.7)
Physical activity	Engage in physical activity outside of work	79.7 (72.7-86.6)	79.3 (77.3-81.4)
Body Mass Index (BMI)	Neither overweight nor obese	35.1 (27.4-42.9)	35.9 (33.1-38.7)
	Overweight	33.1 (25.6-40.6)	32.2 (29.7-34.7)
	Obese	31.8 (23.8-39.8)	31.9 (29.4-34.4)
Smoking status*	Current Smoker	15.0 (9.7-20.3)	25.1 (22.6-27.7)
	Former Smoker	25.3 (18.5-32.0)	21.9 (19.9-23.8)
	Never Smoker	59.7 (52.0-67.5)	53.0 (50.3-55.7)
Heavy alcohol consumption	Men having >2 drinks per day and women having >1 drink per day	7.7 (2.0-13.5)	4.1 (3.0-5.1)
Binge drinking	Men having ≥5drinks on one occasion and women having ≥4 drinks on one occasion	13.6 (6.7-20.4)	16.9 (14.6-19.1)
Veteran status	Ever served on active duty	7.13 (3.9-10.4)	9.2 (7.0-11.4)
Health care plan*	Any coverage	93.3 (89.7-96.9)	82.8 (80.3-85.2)
Personal doctor*	One or more	94.8 (92.1-97.5)	85.1 (82.9-87.2)
Medical costs*	Needed to see a doctor but could not because of cost	9.2 (5.1-13.4)	20.9 (18.4-23.5)

*Indicates statistically significant difference.

Conclusions

The results presented above indicate there are some differences between caregivers of persons with Alzheimer's disease or dementia when compared to other caregivers, both in demographic characteristics and the attributes of care provided. Their care recipients tended to be older than care recipients without Alzheimer's disease or dementia and they also were more often female. Caregivers of persons with Alzheimer's disease or dementia were more likely to provide care for a parent or parent-in-law and were more likely to report that they provided the most help with self-care like moving around or eating, bathing, or dressing compared to caregivers of persons without Alzheimer's disease or dementia. These self-care activities indicate caregivers of persons with Alzheimer's disease or dementia may be providing more intense care than other caregivers. Although both groups of caregivers spent a similar amount of time each week providing care, caregivers of persons with Alzheimer's disease or dementia had provided care for a longer duration than other caregivers. They also were more likely to report that caregiving created stress and that it created or aggravated health problems compared to other caregivers. Despite these higher levels of stress, caregivers of persons with Alzheimer's disease or dementia were no more likely than other caregivers to be classified as having frequent mental distress (defined as 14 or more days of poor mental health in the past 30 days). Conversely, caregivers of persons without Alzheimer's disease or dementia were more likely to report that caregiving created a financial burden than were caregivers of persons with Alzheimer's disease or dementia.

Like their care recipients, caregivers of persons with Alzheimer's disease or dementia tended to be older and were more likely to be female than were other caregivers. Also caregivers of persons with Alzheimer's disease or dementia were more likely to be married or to be the member of an unmarried couple than were other caregivers. They were more likely to report their race and ethnicity as white, non-Hispanic compared to caregivers of persons without Alzheimer's disease or dementia. Caregivers of persons with Alzheimer's disease or dementia were less likely to be current smokers and were more likely to report having health insurance and a personal doctor. They also were less likely than other caregivers to report that they had not seen a doctor when they needed to in the past year because of the cost. This may be related to the older average age of caregivers of persons with Alzheimer's disease or dementia since they were more likely to be eligible for Medicare coverage. On most other demographic and health characteristics, caregivers were similar regardless of the diagnosis of the person to whom they provided care. For example, both groups of caregivers had similar levels of education, household income, and employment. Disability, emotional support, life satisfaction, and general health ratings were all similar across caregivers. The two groups of caregivers did not report significantly different levels of physical activity, overweight or obesity, or heavy or binge drinking.

The 2009 BRFSS data provide a population-based snapshot of caregiving in Illinois, Louisiana, Ohio, and Washington, D.C. and suggest that there may be important differences between caregivers based whether their care recipients have been diagnosed with Alzheimer's disease or dementia. Based on these data, it is

possible that caregivers of persons with Alzheimer’s disease or dementia may need interventions to reduce stress and prevent health problems related to caregiving more than other caregivers. They also may need support for a longer period than other caregivers.

Overall, caregivers of persons with Alzheimer’s disease and dementia were similar across the three states. Individual state data are not included in this report because of the small number of individuals who responded within each state. However, we did run individual states’ data to assess differences.

Some caution should be exercised when interpreting the data presented in this report, particularly when the percentages are small. In some cases a relatively small number of people are used to represent all caregivers within a state and their experiences may not in fact be representative of the underlying population. Nonetheless, the BRFSS is a useful data source that is designed to provide state-level information. If you are interested in having the Caregiver Module added to the BRFSS in your state, contact your state BRFSS coordinator. A complete listing, along with more information about the BRFSS and other topics covered by the survey, is available on the CDC’s BRFSS website, <http://www.cdc.gov/brfss>.

References

1. Arno PS, Levine C, Memmott MM. The economic value of informal caregiving. *Health Affairs* 1999;18:182--8.
2. National Alliance for Caregiving and AARP. *Caregiving in the U.S.* Washington, DC: National Alliance for Caregiving and AARP; 2004. Available at <http://www.caregiving.org/data/04finalreport.pdf>.
3. Talley RC, Crews JE. Framing the public health of caregiving. *Am J Public Health* 2007;97:224-228.
4. Alzheimer’s Association. 2011 Alzheimer’s Disease Facts and Figures. Available at <http://www.alz.org/facts>.
5. DeFries EL, McGuire LC, Andresen EM, Brumback BA, Anderson LA. Caregivers of older adults with cognitive impairment. *Prev Chronic Dis* 2009;6(2). [http://www.cdc.gov/pcd/issues/2009/apr/08_0088.htm.]
6. Neugaard B, Andresen EM, DeFries EL, Talley RC, Crews JE. The characteristics of caregivers & care recipients: North Carolina, 2005. *MMWR* 2007; 56(21):529 – 532. [http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5621a3.htm?s_cid=mm5621a3_e]
7. Remington PL, Smith MY, Williamson DF, Anda RF, Gentry EM, Hogelin GC (1988). Design, Characteristics, and Usefulness of State-Based Behavioral Risk Factor Surveillance: 1981-1987. *Public Health Reports* 103(4) 366-375.